

Iron Filings

The Newsletter of the Canadian Hemochromatosis Society

Fall, 2003



The Disorder

Hemochromatosis is the most common genetic disorder afflicting Canadians. It is a crippling, potentially fatal condition caused by iron overload in the joints and organs. The complications caused by the disorder are preventable.

Our Purpose

The society is dedicated to the dissemination of information about the disorder, and its early diagnosis and treatment.

Inside

From the President	2
Letters	3
Memorial Remembrance	4
Eugene Boyko:	
An Appreciation	5
Treating Symptoms	
Missing Disease	6
Maggie's Message	7
Our Donors	8

Member in the Spotlight: Charles Smedley

CHS and the Scottish Doctor

It was in 1970 that my brother Gordon was so sick. The doctors were treating him for jaundice, but he was getting sicker all the time and not improving. His doctor said they wanted to do an exploratory operation and asked me to ask him if it was OK. He said "Yes," so they opened him up and found that his liver was like an old piece of shoe leather. The doctors thought he was a secret drinker, and he and I both said he wasn't. All the doctors in the Kamloops hospital came to look at his liver, trying to understand why it came to be like it was. A doctor who had just arrived from Scotland said it was caused from hemochromatosis. He had been studying about hemochromatosis in the different clans in Scotland.

My brother died three days later. The Scottish doctor said all his siblings should be tested and that is when I found out I had hemochromatosis. My blood ferritin and iron was higher than my brother's was when he died. The doctors gave me five years to live. After five years they said I might get another five. I am still here after 33 years.

At first I had a weekly phlebotomy for two and a half years. Now I have one every four months. A doctor in Vernon sent me for a phlebotomy on just my hemoglobin reading. He just about killed me. I didn't stay with him after I found out how he was monitoring my blood. I now get a copy of my blood test and have a standing order at the hospital in Kelowna to get a phlebotomy when I think I need it.

My father died in 1956 and he was the same colour and was sick like my brother, so I feel that he died of hemochromatosis. In 1982 I saw an ad in the paper about a hemochromatosis society being formed. I joined a few years later. I received a lot of help from the society, Marie Warder and family over the years. If it was not for them I wouldn't be here today. I had to retire from my job in 1986 because of fatigue and my heart, as my



Charles Smedley, Kelowna Contact

doctor said that I would be that way for the rest of my life. He was right. I also have damage to other organs. I also have a number of nephews who have hemochromatosis.

I decided to become a contact person for the Kelowna area so I could help other people like the society has helped me. The hospital sends people to me for information and support. I put on meetings, take doctor packages out to the doctors and meet with them. I leave brochures at all the drug stores, clinics, and big stores for them to put in their lunchrooms for their employees to read. If I am traveling somewhere, I leave brochures at other hospitals or anywhere that someone will read them.

I hope anyone that reads this will join the society and do whatever he or she can to help get the word out about hemochromatosis. If we all do a little bit then it makes the load a little smaller for the others.

Contact Charles Smedley in Kelowna area, e-mail: chctskelowna@shaw.ca, phone: 250-762-3835

Bio-Iron Conference Produces Results

In the Spring newsletter I put out an appeal for new board members. I am pleased to report that we now have six new and enthusiastic additions to our board. So many projects are underway: the revision of our by-laws and constitution; a five-year plan for the society; a new patient handbook; and a revision of our database.

Our on-going meetings with Canadian Blood Services are finally netting results. I have received a copy of a discussion document from CBS proposing that hemochromatosis patients who meet all the standard CBS screening criteria can donate blood as often as once a week. (Currently, the minimum period between donations is 56 days which makes it useless to patients in their de-ironing phase. Just think about all that extra blood that could be saving lives!) We are very hopeful that this policy will come into effect soon.

In May I attended the biennial Bio-Iron conference in Washington DC. Four hundred researchers and doctors representing 17 countries attended, and many gave presentations. At a hemochromatosis panel discussion, the general consensus was that genetic screening for the general population was not recommended, however all relatives of diagnosed patients should be tested and doctors should be on the alert to screen their own patients who have symptoms of diabetes, heart conditions and arthritis.

I attended the Iron Disorders Institute patient conference (in conjunction with the Bio-Iron conference), and gave an overview of our society's history. Listed are some points of interest from other speakers:

- Hcpidin, a hormone produced in the liver, is an erythroid regulator that blocks iron absorption. It may be a possible help in the treatment of hemochromatosis.
- A genetic test in the USA costs between \$110-125. Canadian Medicare covers tests for all first degree relatives.
- I P6 – (phytic acid), is an iron inhibitor which is present in plant foods such as red grapes, prune juice and raisins.
- HHC patients should be vaccinated against hepatitis A & B.
- Enlarged second and third knuckle joints

are still one of the main indicators of HHC, although the wrist, knees and hips can also be affected. About 63% of those affected with arthritis do not improve with phlebotomies. They could try 1500 mgms of Glucosamine and a topical rub, three times a day for several weeks. If this does not help, then discontinue it.

- Iron in the brain is now associated with Parkinson's, Alzheimer's and Lou Gehrig's disease, and can be detected by MRI. Chelation does not easily remove iron from the brain.
- Iron can also be assimilated by inhalation. *(As tobacco leaves are extremely high in iron, some speculate that this may be the link between smoking and cancer as cancer cells thrive in an iron-rich environment. Ed.)*
- A study financed by NIH (National Institute of Health) shows that males with HHC suffer most with liver problems and impotence and females suffer most from arthritis.

I saw an aphaeresis machine in operation at the NIH hospital. This machine extracts iron much faster with less stress to the body because one's own plasma is returned with added saline. However the machines cost about \$30,000 each and the procedure is not favoured by many of our medical advisors.

The International Association of Haemochromatosis Societies also met in conjunction with the congress and Chris Kieffer, (the president of Iron Disorders Institute in the US) was elected as the new president. The Presidents of the societies of Australia, Great Britain, Ireland, Holland, the Iron Disorder Institute, USA and the American Hemochromatosis Society were present with Ireland a new and welcome addition to the group. We all discussed our organizations and ideas and suggestions were exchanged. At this meeting, the Center of Disease Control in Atlanta also informed us that they are preparing information about hemochromatosis to be included on their website.

I came away with new enthusiasm to help our Society move forward with our awareness message and with the help of our new Board members I feel that we are well on our way to doing just that.

Charm Cottingham, National President

Iron Filings

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Member of the International Association of Hemochromatosis Societies
Charitable Donation #11921 9160 RR 0001

Volunteer Contacts

Volunteers distribute materials, contact media, answer phone queries, etc. We need contacts in outlying areas. We have no contacts in PE, NT, or NU, so call us if you want to help. Thanks for your support.

MEETINGS

Ottawa Support Group

October 7, November 13, December 11, and January 8, 2004, 7-9 pm, Riverside Hospital Boardroom, 1967 Riverside Dr., Ottawa. Parking is \$4.50. Call Marjorie 613-739-9277 or Elaine, 613-521-5897

Richmond Support Group

Members will be notified of next meeting by phone. For information please call the Richmond office at 604-277-5905
Newsletter produced by Chris Petty

www.cdnhemochromatosis.ca

Letters

SHORTLY AFTER I began phlebotomies in October, 2001, my leg muscles became very painful. A year later, after getting no medical help, I went to see Dr. Cheryl Lycette NO. She said I should take 500 mg of magnesium citrate and eight drops of zinc daily. About two months later the pain and soreness in my leg muscles almost went away. The inside knee muscles are still very tender.

I believe the added magnesium is at least a partial cure for the sore leg muscles. I also have been using a warm body rub by Songlines Health Products. It is oil from the emu bird and some other additives in it. A little goes a long way when rubbing and working it into the leg muscles and around the knee joints. I am encouraged by the improvement in my leg muscles.

You mentioned you would write up my story in the Spring newsletter and ask if anyone out there had a similar experience. It would still be a good idea to do it and tell that possibly low magnesium could be a cause for sore muscles. I did not have my magnesium checked until the sore condition had improved, and now the magnesium level is a high normal. The question I am asking is, did the high iron - ferritin cause the magnesium to lower? Perhaps draining blood off may have been the cause. I would like this information to get out to our membership and the public at large. It might be very useful. Thank you and keep up the good work.
G.K., Halifax NS

WHEN I SAW a notice that tables were available for the Qualicum Beach Health and Wellness Fair I decided to see how much interest there was in hemochromatosis.

What a wonderful surprise! Many people were aware of it through family or friends having been diagnosed and many just stopped to ask questions. I gave out well over 100 pamphlets and other articles on it, which I had copied.

We still don't have enough interest for a support group, but we have broken the ice. Who knows what the future holds!

Many thanks to Marg Peters, Nanaimo, and Maggie Barnett, contact person in Courtenay/Comox, for their major help in manning the table. It was a fun experience to be repeated.

Bev Creighton

We appreciate and welcome your letters. In order to fit as many in our newsletter as possible, we must edit for space. Our apologies if our editors took out your best lines.

THE SOCIETY HAS BEEN a key support and information source and helped me immensely when I was first diagnosed. I have a father who we are confident died from undetected Hemochromatosis. He suffered depression for more than 20 years. I have only one brother and a mother and they have both been diagnosed after I urged them to get tested. Again thanks to the society and those who contribute to its valuable work.
L.P., Brampton ON

DOUG WAS DIAGNOSED with hemochromatosis on April 22, 2003. His phlebotomies commenced April 26 and are done twice a week, with a blood test once a week. By June there was marked improvement.

I have known Doug since his birth. We were childhood sweethearts, lived in Comox BC and were married in 1959. He had been born a blue baby with an enlarged heart and spent his first years in a solarium. Despite his difficulties at birth he led an active, energetic life, had lots of energy at work and was a wonderful husband and father. But his general health was never very good.

He spent thirty two years with the RCAF during which time he caught every cold, flu or pneumonia passing his way. Service doctors treated these episode with pills to cure all, but no tests were ever done to find out why they persisted.

He was two months into his six month UN Peace Keeping duty in Egypt in 1974-5

when he thought he was going blind. After coming home, he was troubled with calcium deposits in his left shoulder, so he was sent to Victoria for cortisone shots. More shoulder problems were followed by more shots when the family was transferred to Winnipeg in 1997. It was during this time that he had three episodes of severe leg cramps.

Following this, he had an operation for varicose veins to prevent clotting, but this did nothing to correct the problem. We retired home to Comox in 1986 where he had more operations for varicose veins. This time the left leg was a success but the right leg pains him to this day.

This was the start of a series of incidents, many of which have been described as symptoms of hemochromatosis in the book *The Bronze Killer*.

While at a staff barbecue, Doug choked on a piece of steak which lodged in his esophagus. It remained there for three days before it was removed. Unusual cells were found - Barret's Metaplasia. Endoscopies were done twice a year, and a colonoscopy once.

The worst nightmare hit in March, 2000. Doug was called for supper. "I'm completely deaf in my left ear," he said. In the hours to follow, he was hit with a horrendous flu, the doctor confirmed Doug was stone deaf on the left side. Since then his life has been hell with vertigo and headaches each and every day. He had a catscan done and had a balance test. He was told the (nerve) endings in the left ear, and the area surrounding it were gone. The doctor felt Doug maybe could have had a slight stroke. The vertigo and headaches went on.

From 2000 his sleep became more unrestful to the point of being scary. He had night-

Hemochromatosis

What is it?

The excess storage of iron in the body.

What is the cause?

Primarily hereditary

Most common symptoms

Chronic fatigue, joint pain, irregular heart beat, mood swings and confusion, bronzing of the skin and abdominal pain.

Most common complications

Liver and heart disease, diabetes, arthri-

tis and hormonal irregularities.

Tests required for diagnosis

Serum ferritin, transferrin saturation percentage and genetic testing.

Treatment

Phlebotomy treatments (bloodletting) which are ongoing for life.

Reference reading

The Bronze Killer; The Iron Elephant; Ironic Health; Iron Disorders Institute Guide to Hemochromatosis.

mares. He sometimes was short of temper, probably at being frustrated with all his symptoms.

July, 2002 he ruptured his Achilles tendon. Apart from the pain of it all, here he was now with poor balance, two crutches and one foot.

By Fall he was in bad shape. His hands developed a new tremor, and he had more difficulty with concentration. Each and every morning, I would check to see if he was okay before continuing on with my day. He realized how bad everything was and his doctor referred him to a specialist on a suspicion of Hepatitis C.

Finally Doug saw Dr. Engman in March. Final tests for hemochromatosis would come back from Vancouver by June, he said. Well, they came flying back positive immediately.

April, phlebotomies were started pronto, and hey, I almost have a new man here! Not only does he have a new lease on life, he can ask his specialist any question and he spends more than enough time to provide the answers! We appreciate Dr. Brailey's input, thank heavens for such blessings!

Information has been photocopied and mailed to all family members. Let's hope they all take the time to take the tests. If we can find one, can we save a family?

L.M., Comox BC

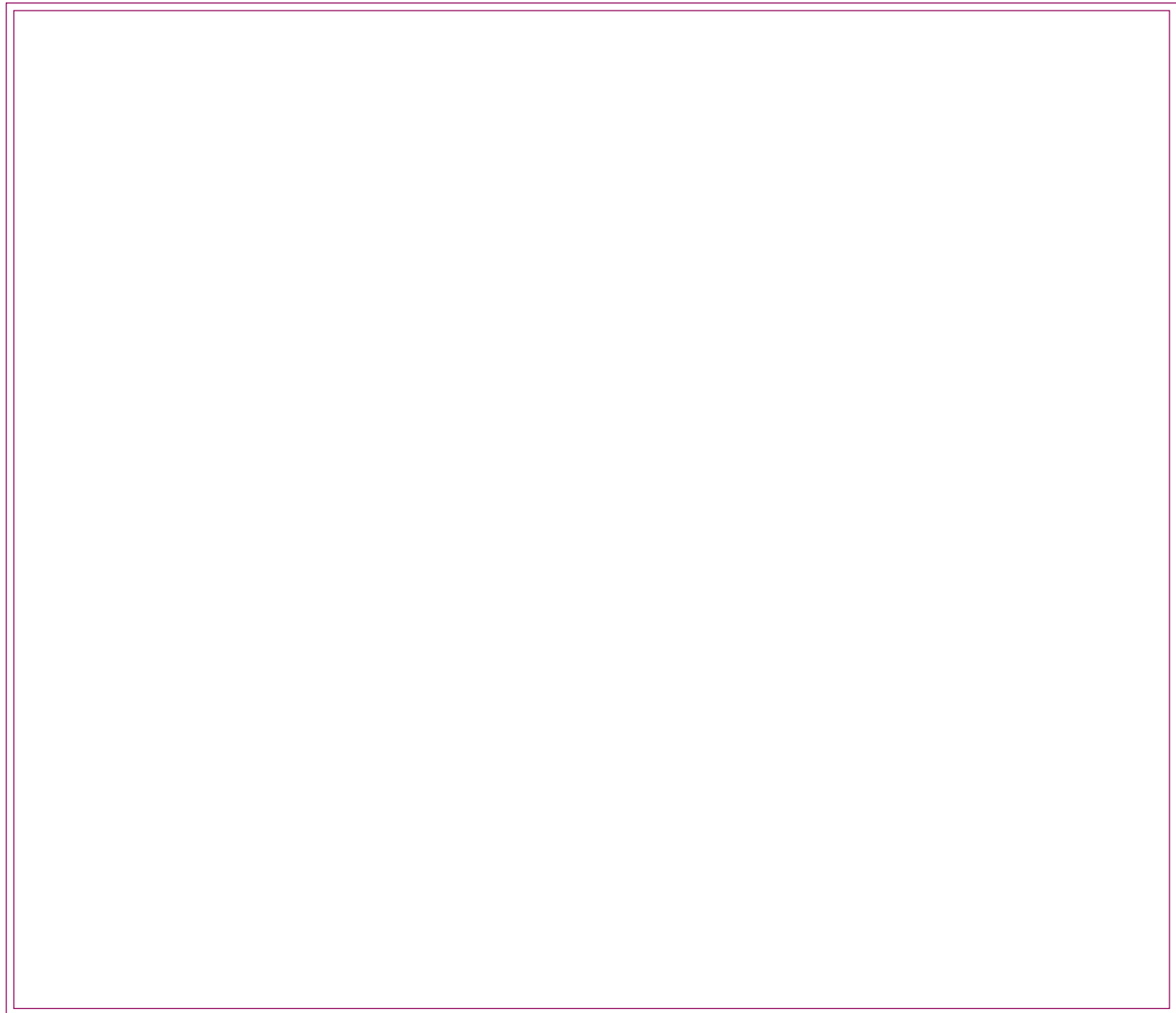
ON MAY 6, 2003 the Comox Valley Nursing Centre held a presentation on hemochromatosis. They showed the HHC video and Dr. D. Lang clarified the clinical aspects of the investigation and management of iron overload. About 25 people attended, asking

questions and sharing their own experiences with the disease. A nurse from St. Joseph's General Hospital in Comox fielded questions about phlebotomies, and a naturapath who has clients with HHC attended as well.

Discussion was beneficial to gaining further insight on both clinical and personal perspectives. Special thanks to the Comox Valley Nursing Centre and nurse Elaine Harvey in assisting with the coordination, publicity and facility arrangements for the event.

M. Barnett, contact person

YOU MUST BE AWARE of the disbelief held by many physicians in the validity of HHC as a genuine medical disorder. I was startled, though, to learn from two friends whose husbands are retired physicians that many see HHC as akin to fibromyalgia. I argued



that such opinion is not based on the research since 1996, when the gene was discovered. So many physicians have little time or interest in reading the literature, which is why I do what I do.
S. A., Calgary AB

FOR EVERY PERSON you educate about the disorder, you create a teacher. It is very hard not to say things people should hear, no matter how many times you get the “iron guy” look. It’s sad that most people only take notice when the damage is done. My employer gives me time during the work schedule to give talks on the subject of HHC. They let me photocopy and make up packages containing all your brochures, which I hand out to all attending. I show the tape that I received from the society and then have a question period afterwards. Surprising how many questions there are. Many thanks to Falconbridge Mines, Kidd Mining Division in Timmins, Ontario.

(Consider them thanked. Ed.)

G.T., Timmims ON

I TESTED POSITIVE for this disorder two years ago. I am a 36-year old female. Since that time we have learned that my mother, aunt and sister also carry the genes. Without the Internet and the CHS I would still be suffering from the early symptoms of fatigue, muscle pain and palpitations. My doctor told me that it was an old man’s disease. I was forced to seek diagnosis outside the country. It has since been confirmed in Canada and I have been treated to reduce my ferritin to appropriate levels.

C.O., Calgary AB

Many of you have told us how much you enjoy the **Letters** section. You can also share your stories and questions with fellow sufferers via our website. In many areas where a support group isn’t feasible, people are finding this “cyber support group” a big help. Check out the forum at:

www.cdnhemochromatosis.ca
and click on the News Board.

Please send your letters to:

**Canadian Hemochromatosis Society
Richmond Caring Place
#272 - 7000 Minoru Boulevard
Richmond, BC Canada V6Y 3Z5
or email:
office@cdnhemochromatosis.ca**

An Appreciation

Eugene Boyko: Loyal Friend and Volunteer

Eugene Boyko was a loyal friend for 17 years and a willing and trusted helper for most of that time. He did not make rash commitments, nor did he enter easily into a friendship. But once he committed to a project or a friend, there was no turning back. As a friend, he would defend you through thick and thin, even if you weren’t always right.

My deepest thanks to Eugene and his wife Del, for their help in running the society, and for their support during the last years of my husband, Tom’s, life.

Eugene’s interest in the society began in 1986 after Del showed him an article in Maclean’s magazine about hemochromatosis. He knew at last what had been wrong with him for years, and he lost no time getting his doctor to carry out the tests.

The article didn’t print the address of the society, but Eugene applied his perseverance and tracked us down. Not long after that, he came to our AGM at the Richmond Inn, right in his hometown. He had been impressed by having his information package delivered to his front door within 20 minutes of that first phone call by our volunteer, Kay Keller.

At that AGM, I recall him telling us a little of his battle with what seemed to be iron overload, and his search for a diagnosis. He said, “I am not joining this society today. I have not yet had the results of my blood tests but if, when I do, they confirm that I have this condition, I shall not only join you ... you will have me the rest of my life!” He kept his promise until failing health made it impossible for him to carry on.

Almost immediately after he joined us, Eugene volunteered to act as co-coordinator and to make posters for the first Hemochromatosis Week in 1987, and Del took charge of assigning jobs to volunteers. Both became dedicated to CHS, and took over many of the responsibilities of the local organization,



Eugene Boyko and Del

leaving me to work on my other dream, the International Association of Haemochromatosis Societies. In due course, Eugene was elected as the third National Chairman of the Canadian Hemochromatosis Society. Eugene served in many capacities over his years with the society, but is remembered chiefly for his tireless efforts towards the creation of the “The Richmond Caring Place,” the unique building that houses our offices, and the fact that our society was one of the first to move into it.

Most CHS people are unfamiliar with Eugene’s early history, of his illustrious career and many travels as a cameraman with the National Film Board of Canada. He became such an integral part of the society and the lives of our members, that most of us think of the CHS and Eugene Boyko as one and the same.

He is sadly missed.

Marie Warder

Treating Symptoms and Missing Disease

By David A. Shaywitz, MD

I met Tom seven days before he died. He was transferred to our hospital with the slim hope that he could receive a combined heart-liver transplant. Donor organs never became available. He died during a desperate resuscitation attempt in our intensive care unit, his unnaturally bronzed 55-year-old body barely visible beneath a tangled mass of tubes, lines and wires. But ultimately, Tom did not die because of the technical limitations of medical hardware.

Rather, he died because two decades ago, when his first symptoms appeared, no one thought to search for their underlying cause.

Tom was in his early 30s when he lost interest in sex and was bothered by achy joints. He saw his doctor, who found Tom's testosterone level to be extremely low. Tom was started on testosterone treatment, as well as over-the-counter anti-inflammatory medication for the arthritis. Tom's libido returned, and his joints improved; the medications seemed to work. Gradually, Tom's skin became darker. He attributed this to a tan, though he spent little time in the sun. A year ago, he noticed difficulty exercising. His abdomen began to swell, and when he could take only a few steps before becoming short of breath, he came to the hospital.

Tom's condition was diagnosed as hemochromatosis, a surprisingly common genetic disorder in which iron builds up in various tissues. When the accumulation is in the pituitary gland, the testosterone level can be affected; accumulation in the joints leads to arthritis; accumulation in the skin darkens the complexion. Iron can also poison the heart and the liver, gravely compromising their function.

This was what happened to Tom. His heart was no longer able to pump blood effectively; his liver was no longer able to detoxify the blood properly or make the factors necessary for blood clotting. The surgeon who opened Tom's chest during the resuscitation effort said simply, "He was bleeding from everywhere."

One of every 300 Americans is estimated

to have hemochromatosis, although many do not have any apparent symptoms.

Hemochromatosis was first described by Dr. Armand Trousseau, a Parisian physician, in 1865. The gene responsible for hereditary hemochromatosis was identified in 1996, but scientists are still not sure how mutations in the gene, designated HFE, cause the symptoms.

While scientists struggle to understand the molecular subtleties of hemochromatosis, the clinical treatment of the disorder remains remarkably primitive: serial phlebotomy. That is, weekly bloodletting. It turns out that removing about a pint of blood a week can prevent excess iron from accumulating, and if started early enough, can often reverse disease symptoms.

If Tom's disease had been diagnosed and phlebotomy begun two decades ago, he might have required testosterone therapy, but he could have avoided the progression of the disease to his liver and his heart.

In other words, if someone had thought to ask why a young, healthy man should suddenly have low testosterone levels and arthritis, Tom might have been saved. Unfortunately, Tom's story will probably become more and more common. As doctors are compelled to see more patients in less time and are encouraged to order minimal testing, there is a pressure to treat patients rather than understand them. Low potassium level? Give potassium supplements. Belly hurt? Here's an antacid. Depressed? Try Prozac.

And more often than not, in the short term, the medications we prescribe work. We have become very good at alleviating symptoms and correcting laboratory abnormalities. We often feel good when this happens, and our patients are often grateful. Indeed, this is what many patients expect when they see a doctor - a couple of lab tests, and a prescription to fix whatever their problem is. But if doctors treat only symptoms, then we really are just the pill pushers our critics describe. As doctors, we have been schooled in science precisely so we can try to understand the root causes of a disease, and not simply provide a salve for its most troublesome

manifestations. It is our responsibility to consider what a particular symptom or collection of symptoms may mean, and our obligation to avoid the increasingly common reflex to "treat and street" the patients we encounter.

The need to look beyond a patient's immediate clinical symptoms and to search intensively for deeper meaning has been and must always remain a defining quality of the medical profession.

~ *From the New York Times, May 20, 2003*

Welcome New Members

Sebert Allen, Ottawa ON
Donald Armitage, Delta BC
Robert Armstrong, Nanaimo BC
Valerie Baggaley, Calgary AB
Suzanne Brodeur, St Madelene QC
Patricia Clark, Toronto ON
Larry Comin, Edson AB
Darlene Conte, Winnipeg MB
Shirley Grant, Port Hawkesbury NS
Rosemary Hales, Toronto ON
John Higgins, Whitehorse YK
Robert J. Jones, Peterborough ON
Kinistino & District Appeal, Kinistino SK
Dawn and Arnold Koberstein, Barrhead AB
Avery LaCourse, Griffith ON
Jennifer Lauener, New Westminster BC
Douglas Mann, Comox BC
Carol Mathews, Calgary AB
G.J. McCaffery, Mississauga ON
James Mcphee, Airdrie AB
Bertin Michaud, Edmundston NB
Arlene Pederson, Allan SK
Audrey Perkins, Hamilton ON
Mike Powley, Surrey BC
Tor Rognmo, Vancouver BC
Karen Smith, Wetaskiwin AB
Merle Taylor, Antigonish NS
TELUS Employee Charitable Giving,
Edmonton AB
Constance Tooby, Victoria BC
John Waring, Parry Sound ON
Gwyneth Westwick, Vancouver BC
Robert Willson, Gatineau QC
Charlotte Yorston, New Glasgow NS

Maggie's Message

by Maggie Campbell

I hope everyone had a wonderful summer! After the busy spring we had at CHS, I know I certainly enjoyed a bit of a breather. Why did we need the rest? Well, as some of you may remember from the Spring newsletter, we held the first annual joint CHS/CBS Awareness Week on May 24.

The event was a success in getting hemochromatosis in the newspaper and improving our relationship with CBS by being 25% of blood donations that day. We saved a lot of lives!

I would like to thank once again the staff and volunteers of the CBS. I would also like to thank Elizabeth Chatwood, Marlene Stasyk, Michael and Nancy English, Sigge Erb, Natasha Sharwood and Charm Cottingham for volunteering their time.

To all of you who came and donated blood, especially those of you who were first time donors, I cannot thank you enough. Both the CHS and CBS are grateful to: Elliot English, Rohan Hazelton, Elizabeth Minish, Chris Petty, David Powley, Marianne Powley, Renee Fleetham, Majid Ghorbani, Bill McLachlan, Marguie Nordman, Sandra Connor, Glencora and Jeremy Twigg, Kate Maliha, Roy Mulder, Liam Everett, Darcy Everett, Suzanne Everett and Ralph McLean.

The event will be going ahead next year (tentatively May 23, 2004), so time your phlebotomies! If you have a CBS blood donor clinic in your town and would like to organize your own event please contact me.

In other news, the fundraising department is busy writing grants and gearing up for the December giving campaign. As always, I ask you to plan your giving and include us on your list. Since we receive no government funding, it is only through your generous gifts and memberships that the CHS is able to continue its life-saving work. If you have any questions on how to plan or direct your gift, contact our office at the numbers listed on page two.

Have a good fall and a Merry Christmas. See you in the spring!

CHS/CBS Awareness Week was a huge success. From top right, clockwise: Charm Cottingham, Dr. Sigfried Erb and Maggie; Irene Day, CBS and Maggie; first time blood donors Elliot English, David Powley and Renee Fleetham.



Enjoy your newsletter!

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Speak Up!

When leaving a message on our toll-free line, 1-877-BAD-IRON, leave your full name and address (spell them out) and your 10-digit phone number. Please speak clearly, as it's very hard to understand some messages.

Good Donations

You can now donate online through our website. Visit www.canadahelps.org. Search "hemo," then click "Donate now." This is a secure site. You can use your credit card with confidence.

When sending money . . .

. . . such as a cheque or Visa number, be sure to let us know what it is for. Money will be automatically entered as a donation unless you specifically tell us it is for a membership or in memory of a loved one.

Support CHS and Raise Awareness of Hemochromatosis

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(\$30, senior \$20, family \$45,
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THANK YOU!

October 2003

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